



Proposal for the Establishment of the South Island Collaborative Care Program for Children & Youth with Health Complexity

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BACKGROUND

The evolution of technology and advancements in medical care have led to improved survival for many previously life-limiting conditions occurring in childhood. These successes have contributed to a burgeoning population of children and youth with chronic and complex medical needs, resulting in substantial healthcare utilization and morbidity, as well as marked burden of caregiving for families. The proportion of children with a chronic condition that interferes with daily activities has increased by >400% since the 1960s (12). Children with special health care needs are broadly defined as the 13-18 % of children that have chronic physical, developmental, behavioral or emotional conditions requiring health care and resources beyond that required by children generally (12).

An important subgroup of these children is composed of those that have multiple chronic health conditions associated with medical fragility, significant functional limitations, and intensive health care needs (9,12). These children and youth with health complexity (CYHC) are thought to comprise approximately 1% of pediatric patients and represent, in many cases, the success of survivorship from extreme prematurity, from multisystem illness and from congenital anomalies. Despite the enormous growth in patient numbers, program planning and evidence-based solutions such as coordinated systems of care for this important population have not grown at an equivalent rate, which have created a mismatch in health care need and existing care systems (11,19).

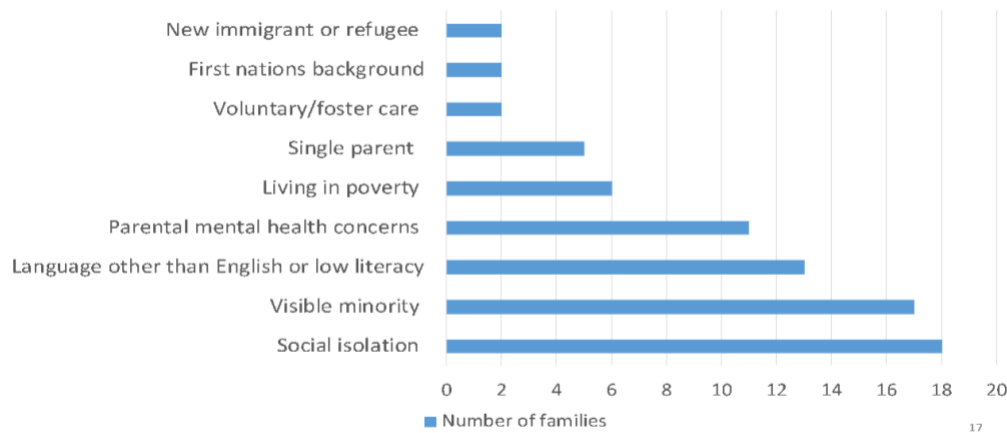
Children and youth with health complexity represent a diverse group of children with a broad spectrum of diagnoses, organ system involvement, needs, limitations and medical fragility. Underlying conditions vary enormously and there is an urgent need for program planning that targets this population and their families. This population often requires intensive health care services, resources, sub-specialists, hospital care, emergency department care and community resources. It is well documented that rates of hospital care and emergency department (ED) visits are higher among children and youth requiring medical technology support (5,7,9,10). With a siloed and overtaxed system of primary, pediatric, community and tertiary care, CYHC are at high risk of missed, fragmented and/or inappropriate care, medical errors, and “avoidable” hospitalizations.

Although CYHC represent a small subset of the pediatric population, they account for disproportionate health care utilization and costs. Mirroring data from the United States, estimates from Ontario suggest that 0.67% of children account for 1/3 of all child health spending and account for one out of every four

pediatric hospital days (10). It is estimated that 32% of admissions are potentially preventable as approximately 64% are attributable to system deficiencies such as medical errors and inadequate care coordination relative to the level complexity of CYHC (22). Studies from the US have also reported that CYHC account for 43% of child deaths and 49% of hospital days (5,25).

This population of children are also noted to frequently live within contexts that include high rates of social complexity, with many social determinants of health putting families and children at risk for inequitable, inaccessible or culturally insensitive care.

Demographics: Psychosocial Complexity of CYHC at BC Children’s Hospital



BC Children’s Hospital Complex Care Program

Only two decades ago, CYHC with current levels of health frailty would have required intensive inpatient care but currently these children are discharged to the care of families who describe immense struggles to coordinate care in a complex and fractured system, to manage technology, administer complex medications, support intense medical and psychosocial needs and to navigate a vast number of care appointments, while trying to meet the demands of everyday life. Families are currently expected to function without navigational support, or a clear path to access care when they need it, and the staggering mental, social, physical, and economic burden on families is well documented (2).

Highlighting families’ needs, BC Children’s Hospital reports that Nursing Support Services have seen a 32% increase in service utilization since 2015 (16). This demand is rising during a time of healthcare and provincial budget and program constraints, compounded by a primary care crisis. Healthcare providers and specialists are overburdened and unable to meet the complex care needs of this growing population of children and youth. In the absence of a well-developed collaborative system of accountable care, the complexity of navigating through the various medical and social needs for this important population is characterized by unmet needs, duplication of service, gaps in service and fragmented care.

Health care providers, particularly in smaller communities, find themselves poorly positioned to provide quality, efficient, well-coordinated care while working as single practitioners in a siloed system. The current system of care requires constant “side of one’s desk” or ad hoc, “work around” solutions to problem solve for families, stay abreast of care plan changes, communicate with other specialized or subspecialized team members in an effort to prevent admissions or Emergency room visits. System

changes and new service design is required to provide quality care in the ambulatory and home setting to improve efficiency, prevent admissions, and reduce burden on families and healthcare providers.

The call for an improved system of care for CYHC and novel program planning to address unmet needs, is receiving increasing national and international recognition amongst healthcare providers, researchers, and advocates. In recognition of the growing impact of this escalating population of children and youth with health complexity, and the extreme need for enhanced coordinated and integrated services and supports for these patients and their families, the province of British Columbia in partnership with Provincial Health Services Authority (PHSA), recently announced the \$221.8 million dollar Slokan Re-Development project in Vancouver. The new centre will provide services to support children and youth living with health complexity. The Slokan project, slated to open in 2028, is a much-needed resource for the lower mainland and will offer some provincial support and opportunities for collaboration with communities, however, it does not adequately address the need that families of CYHC in South Island have for timely, affordable, and accessible services close to home.

It is well documented that the multi-system chronic diseases, technology dependence, and unique, intense, and chronic care needs of CYHC are not adequately met within the current system of care (3,9,12,13). Families are struggling with siloed, episodic, and fragmented care, inadequate support, a scarcity of self-management training for children, and a lack of attention to overall health status of this fragile population. Children and youth with health complexity require innovative, customized, and coordinated systems of care and community supports to improve health outcomes and quality of life (1).

EVIDENCE SUMMARY

Although the language traditionally used for this medically complex population is 'Children with Medical Complexity', the project team has elected to adopt the term "Children and Youth living with Health Complexity". This broader and more inclusive term was developed by a diverse group of provincial stakeholders working on the Slokan Re-Development Project and expands the focus from a medical model of diagnoses and treatment to prioritizing and accurately identifying that medically frail children often have significant additional burdens of social complexity and require care constructed through a lens of social determinants and equity to appropriately meet their needs. Markedly different from the scope of coordination services for typical adult populations, it is critical to note that "care coordination that supports the comprehensive needs of children, youth, and families must be broader than the strictly medical view" (3).

There is no standard definition to identify CYHC, nor a single diagnostic code, which poses significant challenges with gathering data and establishing prevalence for this population (9). Patient identifiers and similar statistics across Canada have not yet been well primed to capture frailty and complexity in pediatrics and limits the understanding of the impact of this population on the healthcare system and their families.

According to a Canadian Institute for Health Information (CIHI) report (7), in 2015–2016, the age-adjusted rate of Children and Youth with Medical Complexity for British Columbia was 802 per 100,000 children and youth, a statistic similar to that found in other research, when using a broad definition.

Estimated numbers of CYHC up to age 19 in South Island, based on the CIHI rate and BC population statistics data (17):

- Estimate for 2020: 570
- Projections for 2022: 581

The CIHI data illustrates the immense need for resources and support for this underserved population, as the population of children is projected to increase over the next few years and the disproportionate share of health system costs must be anticipated.

Although there are various definitions used, CYHC have recently been more strictly defined by sharing the following four characteristics:

1. Complex chronic conditions that are often multi-system and severe;
2. Technologically dependent with substantial functional limitations, dependence on multiple medications, and/or requiring assistance with activities of daily living.
3. High utilization of healthcare services; involvement of multiple healthcare providers and often, frequent, and prolonged hospitalizations.
4. High care needs requiring care provision in the home and care coordination (6).

Based on these more stringent criteria which the program will adopt, according to Dr. Hal Siden (Medical Director of Canuck Place Children's Hospice), it is estimated that there are at least 150 resource intensive children and youth under the age of 18 in South Island. These children and youth are the core target of the proposed program in its initial phases. The project team anticipates that the numbers of CYHC in need are likely much higher than this target group and the ability to grow and expand the program within two years should be built into the program once demand is better understood. Although 150 is not a significant number, as previously indicated, evidence suggests that these children consume a significant amount of health authority resources and pose considerable burden on the system, as well as on families and care providers. Growth in numbers is also predicted and inevitable.

Given their medical complexity, CYHC often receive care from multiple providers. Cohen et al. found that the median number of distinct physicians providing outpatient care to an individual CYHC was 13 (10). Given the high utilization of multiple providers and primary care physicians, coordinated, multi-disciplinary care, and shared care planning are essential to optimize the health of CYHC. This has been well documented in the literature and provides a care model that aligns with Canadian Association of Paediatric Health Centres' (CAPHC) recommendations for current best practice to support this complex population (6,24).

The complexity of the day-to-day life of a family and child in pursuit of meeting needs, optimizing services, and connecting to a wide range of care providers across a range of community, educational and acute care settings is illustrated by this local case study:

CAPHC recommendations:

1. Ensure that a process for clear identification of children and youth with medical complexity is in place to promote equity of services.
2. Build capacity within the health care system to deliver coordinated care that is holistic, comprehensive and family-centred to all children with medical complexity, closer to home .
3. Identify a keyworker and care team for each child with medical complexity to facilitate service planning and care delivery in collaborations with the family/caregiver.
4. Develop and maintain a shared single care plan with common language and clear ownership for children with medical complexity that is accessible and updated in a timely manner .
5. Empower families by proactively supporting them to develop skills, competency and confidence to comprehensively care for their child and to advocate on behalf of their child.
6. Organizations providing services to children with medical complexity must have a strategy to transition between levels of healthcare and different care environments . (Hospital-community-home-school-respite-adult services).

Local Context:

The vast need for coordinated services in South Island was further validated through surveys the project team conducted with 17 families of CYHC, 15 pediatricians and 4 PICU intensivists. Feedback from the 36 participants reported needing support in the following areas, which reflect what is well documented in the literature, and aligns with and informs the proposed model of care.

- Single point of entry/ central point of contact
- Integrated care team (nurse, navigator, social worker, pharmacist)
- Multi-disciplinary care team meetings
- Care coordination/ navigation and liaison between providers
- Standardized digital care plan available to families and providers
- Urgent access complex care clinic
- Social work and mental health support for children and parents
- List of resources
- Virtual care visits/services closer to home
- Support for transition to adult services

Speaking to the lack of adequate supports, of the parents surveyed, only 33% of them were 'satisfied' with the level of care coordination they currently receive. Compounding the issue, only 40% said that

they have a Primary Care Provider involved in the care of their child, leaving families with little support and additional burden falling on other healthcare providers.

“It is hard to feel unseen and unappreciated by the system for the work I am doing and for the work the parents are doing. It feels unjust, as if the system and society care more about MRI machines and surgical equipment and hips and knees and high volume “fixable” well-defined problems than these children and families. They are frail and complex and service intense and society wants to feel good about itself for prolonging life and its extraordinary modern measures done to preserve diversity and then it does not provide the deep commitment needed to support meaningful survival and quality care and a true system. Every day the care of these kids feels like a work around, as if nobody knows they exist. It feels as if these children can only be seen and cared for if they have the “right” disease.”

South Island Pediatrician

- “We as parents to medically complex children also wear the hats of manager, organizer, scheduler, supply manager, nurse, coordinator, and more. It can be overwhelming to plan and organize appointments, specialists, therapies, medication refills, meetings, school planning, IEP’s, etc. the list goes on. We do all of this on top of having other children, jobs, and lives of our own.”
- “Medically complex families are dealing with severe burnout (caregiver fatigue), daily stress, anxiety, PTSD, and the various systems around us are only able to shrug their shoulders about it. It is not healthy for the family to be left to care for medically complex children without ample support. It is a health and safety concern.”
- “A centralized way of supporting the patient and family whether it be through technology or a physical center or both is needed”.
- “Navigation was the most stressful part and I felt very unsupported. I had to work hard and reach out to get all the info I needed.”
- “Health Care is completely coordinated by myself. Communication is a complete barrier for all systems that I have to compensate for.”

South Island Parents of CYHC

Best Practice recommendations, clinical studies and success from other jurisdictions all outline a clear pathway for systemic improvement to provide the quality, coordinated care required by this patient population and their families, who are currently receiving suboptimal care. The risks and mistreatment to patients, families, healthcare providers and the healthcare system of remaining status quo are staggering, costly, and unjust as the population of CYHC is increasing and the system is fractured with provider and family burnout. A new approach is needed, and investment is required to create a local system of care that is truly systematic, ethical, aligned with a lens of equity and which provides care close to home.

PROJECT AIM

To obtain sustainable funding and space for the establishment of the South Island Collaborative Care for Children & Youth with Health Complexity Program (SICC CYHC), an integrated, multi-disciplinary, collaborative care program which will support children and youth with health complexity, and their families by providing timely access to high quality, accessible, trauma informed, planned care coordination and navigation of the complex system of services between hospital, community, and home in a culturally safe environment, both through in person and virtual care.

In improving the system and experience of care for CYHC and their families, the program will also provide much needed support to the specialists, primary care providers, sub-specialists, allied health care providers and community service agencies who are overburdened and often unseen, caring for this underserved population which lacks resources and a system of coordinated care. By providing accessible, quality, preventative, coordinated care in timely manner, it is anticipated that the program will also result in savings to the system through reduced ED visits, number of admissions and length of hospital stays.

With the aforementioned goals, the proposed single point of entry and the assignment of a key worker to support program navigation and access to a collaborative care team, the SICC CYHC Program will facilitate patients and families having accessible and timely access to *the right care, with the right provider, in the right place, at the right time.*

In alignment with the Institute of Health Improvement's quadruple aim, the overarching goals of the SICC CYHC Program are to:

1. **Improve patient health outcomes**
2. **Improve patient and family/ care provider experience**
3. **Reduce healthcare expenditures**
4. **Improve provider experience and sustainable care**

The goals of the SICC CYHC Program align with the following Island Health strategic priorities as outlined in the 2020/21 workplan and, in fact, are required systematic improvements if Island Health is going to meet accreditation standards for ambulatory care and its commitment to quality care for this underserved population:

- 1.1 Indigenous cultural safety and humility is embedded in the design and delivery of quality health care services
- 1.2 Patients and families are included and supported as partners in their health
- 2.2 The majority of patient/client health care needs are met at home or in the community
- 4.2 Timely and appropriate ambulatory services are provided
- 5.1 Health care needs are met for underserved, recently housed individuals or those requiring housing
- 6.1 Specialized MHSU services are provided in the community
- 7.3 Health outcomes are improved and incidence of preventable illness and injured reduced
- 11.1 Use of enabling technologies is maximized

The core principles of SICC CYHC initiative also align with the following Island Health strategic objectives:

- 1.1 Patients, clients and families will be the centre of their own health and care
- 1.3 Teams will provide care to people when and where they need it from birth to end-of-life
- 1.4 Care will be driven by best practice, evidence and data to achieve the highest level of quality and safety
- 3.1 Island Health will achieve the highest level of operational excellence to steward our resources wisely

With increasing and urgent need for support for CYHC close to home, the goal of this initiative is to start small, develop, refine, and expand to create a model of care in South Island that could later be expanded and implemented in Central and North Island, led by local health care providers. Receiving quality care in the community will enhance quality care and substantially reduce the burden and expense for patients and families having to travel to receive care.

MODEL OF CARE

There is an urgent need to support a critical gap in support of parents by implementing effective non-medical support mechanisms to allow the parents/caregivers of children with health complexity to succeed and thrive. The program will provide parents with dedicated, expert resources focused on navigation and care coordination to address the social, psychological and economic costs of caring for a child requiring complex medical care, to a level consistent with a pediatric centre of excellence.

In alignment with the CAPHC Guideline best practice recommendations outlined above, successful models implemented in other jurisdictions, and with the mandate of the provincial Slokan Re-development project, the model for the SICC CYHC Program is being proposed as an initial framework and beacon of local systemic change (6,20). Once funding is obtained, stakeholders will be engaged to establish a project team to further inform the model and workflow development.

- Hours: Monday – Friday 8:30-4:30 initially, with the goal of expanding hours to support accessibility if need dictates and funding allows

Key Program Components:

- Key worker model, providing navigation and coordination
- Single point of entry, central intake
- Patient and family centred quality, wrap around care, providing education/training and psychosocial support for patients, families and caregivers
- Structured clinical intake, assessment and scheduled reviews
- Electronic shared care plans
- Urgent and emergent care referrals and coordination, urgent pediatric assessment
- Multi-disciplinary collaborative care team and integrated case management meetings
- Virtual care
- Evaluation
- Steering committee, with patient partner/family involvement

REFERRAL CRITERIA

The SICC CYHC program will provide full program support to patients up to age 19 who live south of the Malahat. Specific inclusion and exclusion criteria will be defined working with key stakeholders in the project implementation phase. The program will also provide urgent consultation and coordination for patients who are admitted to the pediatric ward and pediatric ICU, regardless of area of residence. Referrals to the program will be accepted from Primary Care Providers (PCP), pediatricians, specialists, neonatologists, PICU physicians and Nursing Support Services nurses.

COLLABORATIVE CARE TEAM

Due to the multifaceted care needs of CYHC, their care team spans various health disciplines and requires the expertise of a multitude of providers including specialists, nurses, pharmacists, social workers, physiotherapists, speech language pathologists, dieticians, occupational therapists and psychiatrists, to name a few. An integrated team approach and multidisciplinary collaboration is essential to reducing siloes, creating efficiencies and providing coordinated, holistic care to improve health status. Studies show that establishing a collaborative complex care team improves health outcomes, including decreasing the length and frequency of hospital admissions, reducing emergency room visits, and decreasing health care costs (8,23). The creation of a collaborative complex care team with each member having clearly defined roles will streamline healthcare provision and improve health outcomes for CYHC in South Island. The core goal of this team will be meaningful engagement with families, navigation, care coordination and recognition of social and psychological needs.

KEY WORKERS - COORDINATION AND NAVIGATION (2 X 1.0 FTE COMPLEX CARE NURSES)

The SICC CYHC Program will improve coordination of care by providing each family with a single point of entry to a key worker who has an in depth understanding of the family's goals, strengths, and needs, services and current care plan. The key worker will coordinate services, help support and empower patients and families, improve communication, and create efficiencies for patients and healthcare teams

by advocating for access to timely, integrated, culturally safe, wrap around care. Creating key worker roles is a vital strategy to reduce barriers and burdens that caregivers/families experience as they navigate a siloed healthcare system.

The key worker will work to a full scope of practice informed by the medical and social circumstances of the family and will serve as a navigator to coordinate service planning and care delivery in collaboration with the family/caregiver and other care providers involved in the child's care. The key worker will build relationships and strategic partnerships within the health authority and with subspecialists, specialists and community partners, leading the coordination of care amongst the complex system of care providers.

The ratio proven successful at BC Children's Hospital in Vancouver, and endorsed by the Slokan Re-development Site proposal, is one key worker to 30 patients and their families (16). Although the SICC CYHC program will be looking at much higher numbers, it is anticipated that the support of the social worker, pharmacist, and program support clerk would greatly increase team capacity and thus the team is modestly proposing two key workers initially as the program builds and workflows are trialed through quality improvement cycles.

Key workers would provide the following supports to patients, families and providers:

- **Assessment and care planning:** Enhance care and communication through a structured program intake assessment, assessing needs and strengths of the patient and family, and goal setting. Conduct routine check-ins and re-evaluation of goals, refer as needed, co-create and maintain comprehensive electronic shared care plans with families, identify and address gaps in service, assess interplay of the social determinants of health, develop tools and strategies to support parents, conduct annual reviews with patients, families and the care team, supporting Advanced Care Planning.
- **Navigation and coordination:** Reduce the burden of care provision, improve care and efficiencies by assisting families to access and navigate key supports and services, coordinate integrated care meetings with specialists and sub-specialists to ensure continuity of care, enhance communication between the care teams, help parents navigate connection to the complex web of resources outside of their child's medical care. Conduct transition strategy planning between the community and inpatient care, coordinate prescriptions with the pharmacist, facilitate families obtaining medical equipment, help to facilitate funding, provide family support and advocacy. Oversee the scheduling of ambulatory care, minimizing the number of visits to the hospital and with care providers.
- **Clinical support and education:** Provide proactive preventative care by conducting clinical assessments, taking vitals, synthesizing, and summarizing the patient's extensive medical history, completing clinical forms. Support urgent patient calls, facilitate urgent care referrals, and participate in integrated case management and multi-disciplinary team meetings. Empower families by providing parent/ family caregiver education and training to support self-management.

- **Program development and quality improvement:** Create and maintain comprehensive resource registry for care providers and families, develop patient care pathways and practice guidelines that guide care coordination at key transition points and which recognize patients and family / caregiver needs. Participate in CYHC Steering Committee, inform program quality improvement.

SOCIAL WORKER: (1.0 FTE)

Given the complexity of CYHC, their developmental, educational, and social needs, the number of psychosocial risk factors many families face, as well the mental duress they are under, support of a social worker is imperative to proactively caring for patients and families. A study by Coquillette et al. found that medical complexity was associated with 6.23-fold greater odds of using social work services and with 8.07 times more hours of services per child than children without complexity (14).

Acknowledgement of the high resource intensity of CYHC, and significant emotional burden for caregivers who experience ongoing cycles of grief and trauma, informs the crucial requirement to appropriately resource the SICC CYHC team with social work support that is sustainable over time. Having the social worker as an integral part of the care team, working in a dyad with the key worker, will also relieve pressure on other healthcare providers who often step into the role of addressing psychosocial support and advocate for resources in the absence of an accessible program social worker, which in turn limits their clinical capacity.

Families with lived experience with CYHC report that at times they intersect with multiple agency social workers, but again find the overwhelming responsibility of coordination of care, advocacy and communication lands with them, the family. Thus, another goal of this position is to streamline communication between the many various social workers involved in CYHC care with the aim of reducing duplication, gaps and increase efficiencies.

The social worker will provide advanced-level clinical psychosocial services and take an expanded, holistic and best practice approach to support patients and parents in their caregiver role, promoting the social and emotional health of families, both in-patient and out-patient. The social worker will serve three primary functions:

- **Assessment and Advocacy:** Conduct comprehensive individual and family psychosocial assessments, assessing stressors, supports and barriers to care. Screen and make referrals related to mental health, developmental and educational concerns. Liaise with the mental health teams and recommend consultation with psychology and psychiatry, as appropriate. Advocate for the patient, family or caregiver for resources within the hospital, school and the community. Provide leadership, guidance, education and consultation to the team and community regarding child welfare concerns and mental health issues. Manage caseload and through participation in integrated case management meetings, provide leadership, guidance, education and consultation to the team and community regarding the care plan and mental health concerns and stressors.

- **System and Knowledge Navigation:** Support parents to navigate services related to the social determinants of health (financial assistance, housing supports, reducing social isolation, employment, education, housing, etc.), build a resource registry, and connect families to psycho-social resources and facilitate referrals and completion of forms and funding.
- **Clinical Counselling:** Provide advanced therapeutic psychosocial intervention through individual counselling to children, adolescents and parents, building on family strengths and providing social and emotional support. Provide family counselling, with a trauma informed lens, around adjustment to diagnosis and treatment, grief and loss, anxiety, depression, substance misuse, crisis intervention, conflict resolution and transition to other hospitals or adult care. Assist patient and family with coping strategies to decrease stress in decision-making around treatment, during treatment and transition back to community.

PHARMACIST: (0.5 FTE)

Children and youth with health complexity are an emerging population in which health care innovation, including medication management, is imperative to improve health care costs and outcomes. It is well documented that CYHC are at risk for substantial polypharmacy and inherent drug-related dangers often resulting in increased emergency department visits (ED) due to adverse drug events (27). To mitigate these dangers, the integration of a clinical pharmacist into the care team is critical for the identification, prevention, and resolution of drug therapy problems and the associated risks, while also helping ensure continuity of care in this population. This role is essential as healthcare providers are often unfamiliar with the multitude of medications prescribed for these patients, putting patients at risk. Parents of CYHC patients are the primary caregivers and are required to provide complex medication regimens that many do not understand or remember accurately, which poses significant risk and requires support.

Current literature documents the benefit of having a clinical pharmacist on the pediatric complex care team citing evidence of the benefits of reduced adverse medication events, medication errors, cost, ED visits, hospital admissions, and duration of hospital stay (Appendix 1).

The pharmacist, providing support as follows, will provide comprehensive medication reconciliation and the development of customized medication plans which promote safe and consistent medication practices across the continuum of care, which will improve the patient's care and quality of life.

- Provide team-based care, assessing and monitoring medications, preventing potential adverse drug interactions, resolving drug therapy problems
- Identification and reduction of patient adherence barriers (E.g., financial)
- Liaising with care providers for care plan implementation to support transitions of care
- Monitoring patients' responses to drug therapy after discharge, or after significant medication changes in the community, titrating medications as necessary
- Provide comprehensive bi-annual medication reconciliation, customized medication plans and education to patients and families
- Provide drug information, recommendations and consultative services to physicians and other team members to improve medication safety systems

- Participating in integrated case management meetings and the Steering Committee

PROGRAM SUPPORT CLERK: (0.6 FTE)

There are substantial administrative requirements to supporting CYHC and their families, in addition to coordinating with stakeholders and supporting the team. The support of a program support clerk is essential as a member of a patient-focused team to create efficiencies and facilitate the care team to work to top of scope. The clerk will provide administrative and clerical support services, including client reception and secretarial support services for the program and clinic staff, having the following responsibilities:

- Receiving and re-directing patient calls, tracking referrals, booking/changing patient appointments with the care team, placing reminder calls, room booking, coordinating specialist's appointments and planned investigations, scheduling coordinated interdisciplinary team meetings
- Faxing lab, prescription and diagnostic requests, scanning documents, processing orders, sending forms to patients, sending telehealth information to patients, troubleshooting telehealth issues, ordering and maintaining program and office supplies
- Maintaining client data, entering information into databases or spreadsheet

PROJECT MANAGER: (1.0 FTE, 18 MONTHS)

Given the broad number of stakeholders which must be engaged, the complexity of the system of care for this patient population, and the model requirements, coupled with the competing priorities of physician and healthcare stakeholders, the support of full FTE project manager for a minimum of 18 months is essential to the successful development and implementation of this project. It is anticipated that project management support will be required for at least 13-15 months pre-implementation to plan the development of clinical processes, care delivery and procedures and another three to five months post implementation to address issues and facilitate the adoption and refinements of the new service model workflows, utilizing quality improvement and change management frameworks. The project manager will also support evaluation, reporting, and facilitating the establishment of a Steering Committee. Once the program has stabilized and workflows have been optimized, the program will be operationalized.

Working alongside the Medical Director of Ambulatory Care, the project manager is responsible for leading and managing the following, including producing all project deliverables, as per below:

Pre-implementation:

- Engage patient/family partners through Patient Voices Network (PVN)
- Engage leadership support, physicians, healthcare providers and community to further inform development of the service model and workflows
- Lead the development of a clinical working group, foster relationship building, utilize change management to positively engage and support stakeholders in the initiative to foster change and reduce resistance

- Lead the strategic development of program and role definitions, workflows, resources, assessment tools, guideline and policy documents
- Plan and chair meetings, manage action items, identify and mitigate risks (pre & post-implementation)
- Apply for Specialist Service Committee (SSC) project funding, write and submit monthly SSC status reports, track and manage project budget, submit sessional payments for all stakeholders
- Arrange training and workflow simulation
- Facilitate privacy impact assessment (PIA) and security risk and threat assessment (STRA), as required
- Build REDCap data base, facilitate set up of logistics: phone, email, etc., obtain equipment

Post Go-Live:

- Lead project team to conduct quality improvement cycles and refine and adapt workflows accordingly to improve the service and attain outcomes
- Support the team through change management approaches and foster team building
- Ensure all stakeholders are engaged, well informed, and supported
- Coordinate successful transition program to operations

Project deliverables:

- Project charter
- Work plan
- Communications plan, program promotions, website development
- Workflows, Guideline and Policy documents
- Executive reports including risk registry
- Metrics developed and evaluation plan
- Program tools, resources and templates: referral form, in-take form, standardized care plan, resource directory, assessment tools, standardized care pathways and algorithms, communication templates
- Establishment of SICC CYHC Steering Committee and Terms of Reference
- Staff trained
- Project close out report

KEY PROGRAM COMPONENTS

As per current best practice, the following are key program components of the SICC CYHC Program which ensure accessible, integrated, and coordinated care that is proactive and tailored to each patient and family's needs and environment. Navigation and coordination roles are the key components of the program and are highlighted above in the key worker job description.

PATIENT/FAMILY PARTNERS

Patients and families are central to the SICC CYHC Program and their input is essential in planning an effective, culturally safe, patient/family centered program providing wrap around care and addressing

current gaps. With a firm commitment to honoring “nothing for us, without us” patient/family partners will be engaged through the Patient Voices Network as valued partners in the creation and ongoing support of the program. Patient/family partners will be engaged in patient journey mapping, focus groups, and informing the model development and workflows. They will also be engaged as active participants in the SICC CYHC Steering Committee and will participate in program evaluation.

SHARED COMPLEX CARE PLAN

A complex care plan is a child and family focused executive summary of all active healthcare issues, and includes critical information such as the medical, psychosocial, and coordination needs of the child, which is designed to meet the child’s and family’s goals and optimize health outcomes. Informed by evidence based best practice, a regularly updated shared care plan acts to bring the multiple members of the care team up to date, improves continuity of care, reduces errors, increases efficiencies by reducing duplication of efforts, and has been shown to reduce overall cost to the family and the health system (23).

Patient centered care plans alleviate the need for parents to repeat their story at each visit, reducing burden and allowing for more time spent on quality care. In surveying parents/caregivers of CYHC, pediatricians, and pediatric interventionists in South Island, all emphasized the necessity of a shared care plan to enhance communication and improve care.

To be effective and to provide availability to families and all multi-disciplinary care providers involved in the child’s care, an electronic shared care plan is necessary. Technology has made online or cloud-based shared care plans available, and access will likely involve the need for a PIA and Security STRA to ensure that Island Health, and patient and family, privacy and security needs are met.

PEDIATRIC RAPID ASSESSMENT

Medically complex children have a range of urgent medical needs that arise unexpectedly. Having rapid access to a physician for addressing escalating issues, ordering tests, streamlining care, providing preventative care and other problem solving, can help prevent avoidable ER visits and admissions. Building in an explicit role for a physician to assist in trouble shooting and to provide rapid assessment is essential to help provide the team with physician expertise and availability, and reduce the sense of crisis that can exist with fragmented care. It is proposed that two hours a day during weekdays, a scheduled pediatrician will be available as an in-house resource to support the role of urgent assessment, interdisciplinary care delivery, and problem solving.

VIRTUAL CARE

Given the complexity of the patient population and challenges with transporting technologically dependent children, the goal of the program is providing care in the home where possible. Virtual care provides an affordable, accessible, and sustainable solution to connect patients/families to healthcare providers and information through technology. Virtual care reduces the burden of travel on families and may help prevent hospital visits which can be traumatizing to CYHC.

The use of virtual care also creates efficiencies in the system by reducing travel time for staff, which supports the ability to increase capacity. Virtual care provides patients and families with the security that someone is monitoring their care which helps build confidence and empower families. Examples which may inform options for the SICC project include:

- **BC Virtual Visit:** to securely support virtual visits with families and care providers in the home with the ability to support collaborative case management with multiple care providers.
- **Remote patient monitoring (RPM):** Monitoring solutions to support at-risk patients remotely and to coach and educate patients/families on health conditions to support co-management. Supporting conditions such as heart failure, chronic kidney disease, hypertension, respiratory insufficiency, COVID-19, progressive life-limiting condition, RPM provides clinical staff the ability to monitor and trend metrics (temperature, blood pressure, weight, O2 saturation) and symptoms safely and effectively. Supporting symptom management will help to prevent hospitalizations and help inform families with the decision of when to bring their child into care at the right time.

STEERING COMMITTEE

The SICC CYHC Program will establish a multi-disciplinary group of healthcare professionals and patient/family partners to provide strategic direction, governance, and evaluate the effectiveness of activities related to the program. With collaborative patient and family centered care as a guiding principle, and with a shared vision and goals, the steering committee will ensure system-wide coordination, identify and resolve issues, and advance innovative approaches for the enhanced care of CYHC and their families.

PROGRAM OUTCOMES/ EVALUATION

The overarching goal of the program is to provide coordinated, collaborative care in order to improve health outcomes and care experience for patients and their families. By addressing the gaps in the existing fragmented system of care, the program aims to improve the experience not only for patients and parents, but also for specialists and healthcare providers by alleviating some of the significant burdens of care provision.

It is also anticipated that a proactive, coordinated system of collaborative care will help reduce the prevalence of Emergency Department (ED) visits, hospital admissions and reduce length of stay as has been shown following other interventions that improve care coordination for CYHC (11). This data is internationally recognized as challenging to collect and evaluate as, due to the lack of a standardized definition for these patients and the lack of a specific diagnostic code or formal tracking mechanism, acquiring and measuring data on these patients is difficult. Where possible, baseline metrics will be obtained from the health authority, as well as patients, parents, caregivers, providers, as all are impacted by the current burden of care.

It is essential to note that strict “return on investment measures” miss the important benefits of programs and initiatives in complex care, which are realized over years. Terms such as “Value of

Investment” have been proposed to highlight the intangible assets that are essential to a complex system’s effectiveness. Intangible assets can include knowledge, processes, organizational structure, and collaborative integrated processes. It is well recognized that in complex care, value is multi-faceted, depends on the audience and requires a long view with a strong sense of compelling social advocacy (15, 18,26).

PROGRAM METRICS

The following metrics are being proposed for monitoring and evaluation:

- # of patients registered with the program
- # of scheduled key worker visits
- # of scheduled social work visits
- # of consults with the pharmacist
- # of in home visits
- # of new intake assessments
- # of telehealth visits
- # of remote patient monitoring metrics gathered
- # of shared care plans created
- # of urgent calls to clinical key worker
- # of collaborative care case meetings
- # of calls to pediatricians for urgent assessment

PATIENTS, PARENTS & CAREGIVER ASSESSMENTS

The following assessments will be considered in support and assessment of patients and family experience:

- AOL SF-36
- CPCHILD
- PedsQL
- GADS- 7
- PHQ9
- FECC
- CCMT
- SICC CYHC program evaluation

PROVIDER METRICS

The following assessments will be considered in assessing provider experience:

- NASA Task Load Index
- Measurement of care coordination
- SICC CYHC team survey

SYSTEM IMPACTS

Despite the many challenges with data gathering on CYHC, the program will strive to report on the following for the program population, based on correlation of resource intense children and youth with high number of admissions.

- # of ED visits
- # of re-admissions
- LOS
- # of PICU admissions

BUDGET AND SUPPORTS

The proposed model requires sustainable funding for provision of the following health care team, as well as leadership and change management sponsorship, provision of equipment and logistics, and program support.

STAFFING

The following providers are required to adequately support the target group of patients and families, to provide coordinated, collaborative, integrated, wrap around care and to improve health outcomes:

Role	FTE	Cost*	Note
DC2 Complex Care nurse	1.0 FTE x 2	\$297,064	1
Social Worker, Grade II	1.0 FTE	\$146, 647	1
Pharmacist	0.5 FTE	\$81, 675	3
Program Support Clerk	0.6 FTE	\$69, 996	1
Project Manager, grid 9 (18 months)	1.0 FTE	\$216, 355	2
Sessional Funding for Pediatricians	2 hrs per day, M-F	\$41, 332	4

Notes:

- 1) Works 5 days a week, M-F, 8 hrs a day with relief and stats
- 2) Costed for 18 months, M-F, 8 hrs a day, stats but no relief
- 3) No relief or stats
- 4) Sessional Funding: Specialist sessional funding for urgent on call care, 2 hours x 5 days a week

LEADERSHIP AND PROGRAM SUPPORT

In addition to funding for staffing provision, the following supports and endorsements are required to promote and adequately sustain the program and support to change management:

- **Executive Sponsorship:** Clear and visible executive sponsorship to drive a program forward, share vision for change, mobilize teams, and lend credibility to the change project
- **Manager:** HR, scheduling, leave forms, limited program scope as necessary until program operationalizes from project manager to manager three to five months post go-live, after which time manager would provide leadership support
- **Allied healthcare support:** Formal access and support for collaborative care planning with the following teams: PICU team, pediatric team, a dietician, OT, RT, Queen Alexander early intervention teams, neuromuscular team and others as required

LOGISTICS

- **Clinical Space:** One wheelchair accessible examination room, access to a waiting room, office space for 5 team members with 5 phones and computer workstations, 1 multi-purpose printer with fax and scanner, virtual care equipment as required, Cerner and REDCap access as necessary, Dragon dictation
- **Equipment & Supplies:** Wheelchair accessible scale, stadiometer, supine length measurement scale, otoscope, stethoscope, BP cuffs of varying size, measuring tapes, ophthalmoscope, oxygen saturation monitor, examination bed, miscellaneous minor medical supplies budget, office supplies

STAKEHOLDERS

Due to the complex nature of the care provision that CYHC requires from care providers, the healthcare system and community services, a broad number of multi-disciplinary stakeholders will have to be engaged in both the project planning process and program operations to ensure a comprehensive, inclusive initiative and to support successful change management.

CORE STAKEHOLDER GROUP

- **Island Health stakeholders/programs:** VGH Site Director, Clinical Operations, VGH Director, Clinical Operations, Executive Director, Regional Child, Youth & Family, Medical Director, Ambulatory Care, Medical Director, Pediatrics, Director, Child & Youth Strategy, CYF Rehabilitation Services Leadership Team, Manager, Pediatrics, PICU team, Respiratory Therapy, Queen Alexandra Centre for Children's Health teams, Dietician, Social Work, Pharmacy, Surgical Services, Decision Support, Clinical Informatics Virtual Care Services, Pediatric Quality Council, Professional Practice, Learning and Performance Support, Quality and Process Improvement, Information Security, Information Stewardship, Access & Privacy
- Patient/family partners
- South Island pediatricians
- Primary care providers
- Nursing Support Services, PHSA
- Bayshore Healthcare Nursing
- MCFD: Children and Youth with Special Needs Program (CYSN)
- MCFD: At Home Program
- BC Children's Hospital Complex Care Team, Sunny Hill and Canuck Place

BROAD STAKEHOLDER GROUP

- Sub-specialists: neurologists, cardiologists, respirologists, orthopedic surgeons, gastroenterologists, general surgeons, biochemical disease physicians
- Island Health: Child & Youth Mental Health, Developmental Disability Mental Health Team, audiology
- Slocan Site Re-development Project Team
- Palliative care teams
- Community Health Services
- Wound care nurse
- Schools
- Jeneece Place
- Children's Health Foundation of Vancouver Island
- Mimi's House, Children's Respite Support Society
- Community Living Victoria
- Community Living BC
- Ministry of Health
- Ministry of Child and Family Development
- Ministry of Mental Health and Addictions
- Ministry of Education and Child Care
- Ministry of Social Development and Poverty Reduction

PROJECT TIMELINES

Once funding is approved and a project manager is hired, it is anticipated that the project will require a minimum of 13-15 months to plan the implementation, workflows and define scope as per the program deliverables, given the large number of stakeholders involved, complexity of CYHC needs, resources that need to be developed and the system of change required.

The clinical team would be hired sufficiently ahead of go-live so that they are able to inform and collaborate on the program development. Post go-live, another three to five months will be required to test and refine workflows and stabilize the program before it is operationalized.

ISSUES

A SWOT analysis was conducted for this initiative (Appendix 2). There is currently heightened awareness and recognized need to provide adequate resources and funding support to improve care for the growing population of children and youth with health complexities and their families, who are currently very underserved. Despite the enormous opportunity and political will, there are a couple of recognized constraints that must be overcome to ensure that this population receives the care they deserve to improve patients experience and outcomes.

- To eliminate the risk of being yet another abandoned pilot project, this initiative requires a commitment to sustainable funding, to supporting quality improvement, and to a vision of expansion and growth as need dictates and as the project demonstrates success (4).
- Supporting this complex population of CYHC will require a care team with complex care experience, and training may be required to support the expertise necessary, particularly given the current nursing shortage, which poses a potential risk to recruitment.
- Physical space is a precious resource within Victoria General Hospital, built at a time when the ambulatory care needs of the South Island's future patients and families could not be anticipated. However adequate space for the program is essential to support patient centred coordinated care.

The CYHC SICC project can act as a flagship project and aspirational initiative in moving forward coordinated care of the complex and frail child within the context of their family, and close to home. Advocating for the underrecognized CYHC patient population in the South Island is essential to pediatric programming to ensure comprehensive quality care now, and a vision of excellence for the future. The model can act as a visionary springboard to develop coordinated care models further upisland. Sustainable funding, space, staff, and resources are required for success.

FUTURE VISION

Given the vast need for support for this vulnerable and underserved population of children and youth, the vision for the program is that, once proven, it will expand to provide more comprehensive service provision across the continuum of care and spread regionally to meet the needs of patients and families close to home across the island.

- **Expansion:** Once the program in South Island has been refined and outcomes evaluated, hours and services will be expanded, if demand dictates and funding allows. Once the model is proven successful, the aspirational goal is to replicate the model in Central and North Island.
- **Clinical Care:** In alignment with the concept of creating a pediatric centre of excellence and with services provided at BC Children's Hospital, the addition of a clinical Physician or Nurse Practitioner to provide full scope clinical care is anticipated for the next phase of the project in order to support patients and families to receive comprehensive, quality, wrap around care in one place in their local community. This will also further reduce the burden on acute care and ED departments, as well as Primary Care providers.
- **Partnership:** Discussions are underway with the Vancouver Slokan Site Redevelopment Project Team about potentially serving as a pilot project for them to trial the community navigational model and later, to serve as a community partner once their program is up and running. The SICC CYHM project team will be collaborating with the Slokan team to discuss future planning and development, and to ensure alignment with provincial direction and deliverables.



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APPENDICES

1	SBAR Pharmacy	 SBAR - Clinical Pharmacist for
2	SWOT Analysis	 CYHC SWOT final.docx